INITIAL FINDINGS - THE EXPERIENCE OF PLAY OF 6-12 YEAR OLDS WITH CEREBRAL PALSY

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SUMMARY

• Background literature about play
• An overview of the research philosophy and methodology
• Discussion surrounding the design and implementation of research with children who have high levels of physical disability and communication difficulties.
• Discussion of initial findings of the experience of play for children with high levels of physical disability due to Cerebral Palsy and the impact of this upon practice.
BACKGROUND

WHAT IS PLAY?
 WHY IS PLAY IMPORTANT?
 WHAT DO WE KNOW ALREADY?
 WHAT IS THE GAP?
SO WHAT IS PLAY?

- Freedom (Schiller 1954).
- Choice (Sheridan et al. 2011)
- Control (Nuemann 1971)
- Framing (Bundy 2012)
- Not work? (Wing 1995)
- Not with adults? (King 1979)
- Always fun? (Sheridan et al. 2011)
WHY IS PLAY IMPORTANT?

Primary occupation (Chiarello et al. 2006)
Every child has a right to play (UNICEF, article 31)
ICF (World Health Organisation, 2007)
WHAT DO WE KNOW ALREADY?

• Children with disabilities are reported to play less than their typically developing peers (Whittingham et al. 2010, Chiarello et al. 2006)

• Young people with physical disabilities reported play to include: interactive play, onlooker play; play alone; and play with adult (Tamm & Skar 2000)

• Interviews with parents suggest that children with CP may engage in play: vicariously, through communication, through therapy. (Graham et al. 2015)

• Engagement despite limited performance (Polatakjo et al. 2007).
WHAT’S THE GAP?

Can you think of an example where you’ve observed a child with Cerebral Palsy playing differently to a typically developing child?

Multiple perspectives of play- McInnes et al. 2009)

Image from Scherzi Studios
METHODOLOGY - IPA
INTERPRETIVE PHENOMENOLOGICAL ANALYSIS
**Ontology - Minimal Hermeneutic Realist**

- One reality in the world but this is understood and its nature is recognised within individual contexts. (Heidegger's perspective of reality as described by Larkin et al. 2006).

**Epistemology - Constructionism**

- Knowledge is constructed and influenced by society and our interactions with others (Crotty 2003). The focus is on the *person-in-context* (Larkin et al. 2006).

**Theoretical Perspective - Interpretivism**

- The study is based on interpretation of the meaning of a phenomenon (Finlay & Ballinger 2006).

**Methodology - IPA**

- Interpretative Phenomenological Analysis (IPA) aims to understand and interpret the meaning of a lived experience of a particular phenomena (Smith 2008). IPA includes phenomenology, hermeneutics and an ideographic approach.
Tim is a 19 year old with quadriplegic CP, GMFCS 5, who uses a dynavox and head switches to communicate. Tim requested, and provided written consent, for his name to be used as a research advocate.

Rose (pseudonym) is an 8 year old with quadriplegic Cerebral Palsy, GMFCS 3, who uses direct access to an iPad to communicate.

Tim reviewed and commented on the design for participant recruitment. This led to the use of symbols with text for child information and clear bold colours.

Rose thought videoing children and allowing them to use toys and photos to show the researcher what they meant was a good idea to help them talk about play.
WHY IS THIS IMPORTANT?

‘My name is Tim. I am in a wheelchair and I talk with AAC.

I wanted to help out because I feel that play can help children with CP to understand about who they are inside.’
RESEARCH DESIGN

Information about the research project- What do you feel and say about play?

You have been invited to join in with a research project looking at how you find play and what you think and feel about it. You do not have to take part. If you choose to, this is what will happen:

Naomi will come to meet you. Naomi is studying at university and wants to ask you about play.

You can talk to Naomi about the project.

You can choose if you would like to join in, you don’t have to. If you decide to join in she will ask you to say you agree on a form.

Naomi will ask your parents to fill in a form about your age, how many brothers and sisters you have and your level of disability.
After Naomi has met you she will come to your house between 2 and 3 more times to talk to you about play.

Naomi will video you playing for 5-10 minutes. You can choose what you play and who with.

Naomi will sit and talk to you about play for around 1 hour.
We will look at the video of you playing and talk about it.

You can choose to show Naomi your toys to talk about play.

You can choose to show Naomi photos to talk about play.
Naomi will video the chat to make sure she can write down and think about what you said. She will delete this when the project is finished.

You can stop or have a break at any time by telling Naomi.

When the project is finished Naomi will tell you what you and all the other children who join in say about play in a short document, she will not use your name to make sure no one can tell who you are. If you would like to join in or have questions please talk to Naomi. Phone- 07494 760905 Email- n.graham@brighton.ac.uk

If you tell Naomi about any harm you or someone else is experiencing she will tell this to professionals who can help. Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the University of Brighton, and London Research Ethics Committee. I cannot promise the study will help you, but the information we get might help tell occupational therapists how you feel about playing.
FINDINGS

Daniel (pseudonym) is a 9 year old boy with quadriplegic Cerebral Palsy. He participated in the initial interview using his eye gaze communication device and then in the subsequent two interviews through speech.

Abi (pseudonym) is an 11 year old girl with quadriplegic Cerebral Palsy and dystonia. Abi participated in the interviews through speech.
‘N- So, Daniel, you know when it’s tricky to press that one, how does it feel when you’re playing?  
D- very angry  
N- can you tell me a bit more about what’s in your head, what are you thinking?  
D- this is a stupid button’

‘I like being a secret agent…I like to be a secret agent’  
‘I save all the people in the world’  
‘superheros like me’

N- ‘Okay, and how does it feel when people play it wrong?  
D- a bit annoying  
N- a bit annoying  
D- Yeah  
N- Yeah, and then when, do they get it right eventually?  
D- mm, sometimes  
N- and then does it feel better?  
D- yeah’
DANIEL

Drive to participate- energy, Competition

Emotional variance- Positive emotion, Negative emotions, Help: frustrating vs. like it

Sense of Self- In shared experience, Self-concept as hero/rescuer, Role as helper, Belonging to him, Being heard

Reality vs. Imagination- Drawing on reality in imaginary games, It’s just a game

Acceptance and Control- Power to self- asserting control, Watching vs. playing, Shared experience, Responsibility-others taking over

Self efficacy- Practice of physical skills, Problem solving/ adapting play
If people don’t know me, [who I think] have cerebral palsy or another condition [I can say] ‘you got Cerebral Palsy? and if you’ve got that you’re my friend’, so yes it’s different really. I want to meet people with Cerebral Palsy.

A- no, I’m just disabled and I want to put a wheelchair on it
N- you’ve put a wheelchair on it
A- I don’t know how to put a wheelchair on it
N- so in the game you’re walking
A- yeah and put in a chair, I don’t know how

N- so when, you know when you said you were watching before?
A- yeah but now I play
N- now you play, when you were watching were you still talking to people?
A- No, I was like being a mana… not a manager, I don’t know, no not an audience, I just want to play, I want to play but I want to be really safe, so that’s why.
ABI

Friends with others who have CP - they understand Wheelchair as part of me - Important, in games I do it - helpers as part of play, adaptive equipment Conflict - Playing but not playing

N- ok, so who helps you roll the dice? A- I do it on my own, do you remember, shut the box. (indicating back to game where Abi rolled the dice), like that, rolling the dice. N- Rolling the dice like that, but in shut the box I had, I was holding your hand A- oh yeah N- but I was just, I was just helping? A- yeah
IMPACT

DO YOU FEEL THERE ARE PLAY OPPORTUNITIES BEING MISSED IN PRACTICE?
IMPLICATIONS FOR OCCUPATIONAL THERAPY

DO WE NEED TO WIDEN THE PLAY DEFINITION?
ANY QUESTIONS?

THANK-YOU TO ASSOCIATE PROF. ANNE MANDY DR CHANNINE CLARKE DR DIANE SELLERS
REFERENCES


